SET YOUR CALENDAR FOR ANOTHER RETREAT!
AUGUST 14 to 19, 2016

Winter, 2016

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Registration begins early 2016; watch for application brochures.

We need to find a relief camp helper for 2016: one all-around go-to-person who will work with camp staff, double-check audio-video and condition of program locations and arrange use of borrowed equipment and on-site transportation.

If you know of a talented person (or yourself) willing to be a general field manager for the Retreat, please let Sue know.
Sue.Brandon@q.com
Post-Polio survivors who’ve had the courage and energy to come out for a Clinic, Support Group or Conference this year, have told us how left out and depressed they’ve felt for lack of contact with others in their situation.

Thus, our mission is to continue providing information, education, fun and inspiration to those folks and others we continue to meet.

As our group gets older and passes on, we are now finding younger folks who had Polio in other countries.

If each of us will just talk about Post-Polio wherever we are, we run into people who say, “I know someone who had polio.” Let’s just remember... let’s not be silent. Spread the word and invite them to participate with us! The more the merrier!
COLUMNISTS WEIGH IN ON FUTURE LIFE WITH A POLIO SURVIVOR

Reprinted with permission from Post-Polio Health (Vol. 31, No. 2 – Spring)

The following question has come to Post-Polio Health International a number of times via phone, email and letter. We asked our regular Post-Polio Health columnists Frederick M. Maynard, MD; Rhoda Olkin, PhD; and Stephanie Machell, PsyD, to comment on it for our readers.

QUESTION: I am dating a woman who had polio, but if you didn’t know it, you could not tell it. We are both in our late 20s and I am very interested in her. I have heard about post-polio syndrome and am wondering what I may expect in our future years if I marry her.

Dr. Maynard’s response: People with a history of polio in childhood who “pass” as normal and able-bodied in their 20’s are at risk of developing new health problems during their middle-age and later life. These problems are known as the late effects of polio and include post-polio syndrome (PPS), which is a slow weakening of affected muscles many years after the polio infection and recovery.

Other common problems are excessive fatigue and musculoskeletal pain problems. The likelihood of developing symptoms and their severity are both related to the extent and severity of initial paralytic polio and to one’s personal lifestyle and health behaviors.

In general the late effects of polio do not significantly shorten a person’s expected life span, nor should they cause one to avoid a long-term commitment to someone they love because of fear of excessive disablement in the future. There has been a lot written about the late effects of polio, and by learning about them one can often postpone, prevent or minimize their occurrence and can make timely lifestyle adaptations to them in order to prevent their significant interference with having a high quality of life.

Please read about the late effects of polio and discuss them with your friend. By having an honest and supportive attitude about her history of polio, you will gain a special intimacy and will be in a great position to assist her in maintaining optimal health and function into your older years.

Dr. Olkin’s response: Good for you for being honest about your concerns! No one can tell you what the future will be for her, whether she will develop any post-polio symptoms (pain, fatigue, new weakness) or not. Of course, marrying anyone brings the possibility that the person will develop future infirmities, which is why there is the whole “for better or worse, in sickness or in health” part of vows.

What is possible for the woman you are dating is that she had a mild case with few aftereffects. There may be some weakness that is not very apparent, which could be more apparent with age, as nerve axons naturally die off.

But given that she is starting from a place of relative strength, it might not be that noticeable. She might get a bit
more fatigued than her peers without polio, but again it won’t be too intrusive on activities of daily living. But predicting what will happen is not the right question, since the future with any partner brings unknown risks. So, you have to ask yourself: “If in twenty to thirty years ... would I still want to marry her?” What goes in the missing spot could be:

- She develops sufficient leg weakness that she uses a cane, or crutches, or a scooter or a wheelchair.
- Her fatigue means she naps every day.
- She is unable to work and take care of children due to fatigue, so you make hard choices about income levels, or number of children to have, or using income to hire help.
- She loses balance and falls more easily, and breaks bones, and you have to take care of her intensively for a couple of months.
- You have to modify your house for thousands of dollars to put in ramps and grab bars and wider doors and lower counters.
- She develops a circle of friends with disabilities, and you find that disability topics become a major topic in your household.
- She becomes an activist in disability rights.
- She needs to, but refuses to, use assistive technology such as a scooter, and thus you no longer go to museums or large stores or shopping malls or walks together.

Are any of these likely? No one knows. But if you are not able to think about a future in which you could handle any of these scenarios, then don’t sign up. You would be doing both of you a favor by being honest with yourself.

**Dr. Machell’s response:** All you can know with certainty is that having had polio she is eligible to develop post-polio syndrome. I’ve known polio survivors whose polio was all but invisible in their late 20’s who went on to develop severe PPS. I’ve known others who were always more visibly disabled but whose PPS was relatively mild.

Some polio survivors I’ve known developed PPS relatively early. Some developed it later. Some never developed it at all. And some developed another disabling or chronic condition in addition to or instead of PPS.

And some polio survivors’ spouses become chronically ill or disabled. Or die young.

At any moment of any day of our lives all of us, including yourself or any woman you might marry, are eligible to develop a disability or a chronic illness. Whether or not we become disabled, all of us will age. As we do, our appearance will most certainly change, along with some or all of our physical and cognitive abilities.

Some of us will age well. Some of us won’t. Some of us won’t live long enough to find out.

Marriage is a leap of faith into a great unknown. However happy, well-matched, and/or in love you may be, all marriages face challenges. A spouse’s disability is a major challenge for any marriage. Some marriages,
often but not always the ones that are already troubled, end as a result. Some, often but not always the ones that are already strong, come through the crisis stronger. And some, often but not always the ones that are neither great nor dreadful, continue as they always have.

No matter how much you know about the possibilities, the future is uncertain. And no matter who you choose to marry, you may regret your choice. To make the best decision possible it helps to be aware of your own feelings, values and beliefs.

Does knowing that this particular woman might someday develop PPS overshadow your current feelings about her and the life you could have together? For just a moment, imagine your future if she does develop PPS. Imagine living with a wife who has less energy and more pain, one that needs to use a brace, or crutches, or a wheelchair or scooter. Imagine that she can do less in the home, that she can no longer work that she is less able to engage in active leisure activities. That she can no longer pass as temporarily able-bodied.

Still interested in her? If not, better you know now, when you both have the opportunity to make different choices. If so, you may have realized that no matter what your futures hold, you can’t imagine yours without her in it – which is the best reason to marry anyone. Whatever you decide, I wish you and her all the best.

* * * * *

This is only part of our Jefferson County DA’s FRAUD WARNINGS from the Fall Conference

Use close-fitting pouch instead of purse or wallet when you’re out.

Never carry Social Security Card or checkbook out of house.
Carry only one credit card or check.

Get on Colorado “No Call” List.
1-800-309-7041, 303-776.2678 or www.coloradonocall.com

OPT-OUT for pre-approved credit card offers - 1-888-567-8688.

OPT-OUT for “convenience checks” from your own credit card issuers.

Hang up on marketing and contest offers. Don’t open like e-mails,……, Your friend ISN’T stranded abroad!

Don’t forget to shred, shred, and shred!
My Bum Left Leg
By Dick Campbell

Definition: "bum lamb" The weaker of twin baby lambs, needing extra care

After walking early and running before I was the age of one
The day soon came, when I could not stand
The hidden whispers of the word not spoken
A parent's deepest fear, a spinal tap to just make sure
Yes I'm sorry, it's polio, IT'S POLIO
So came my bed in that "Ward"
Where I could only see my brothers and sisters at a distance
Wrapped in heated blankets and sweating 'til I cried
The questions, would there be others in the family, or was I the only "bum lamb?"
But Dr. Salk, he found the answer; he found the "miracle cure"
And because of me, my siblings were first to get IT
The first to get in line, the first to feel secure

I did not know that crutches and braces were not normal
Nor the awkwardness of my gait
But my brothers knew that I could not run
So they took turns throwing me across the yard, or swinging me in a circle
Held by only wrist and brace
So I felt the freedom of a bird, so I learned to fly
And to accept myself as I was, with a minimum of grace

Mom and Dad, they raised no slackers, they expected "nothing but your best"
So the day came when I threw away the crutches and then followed with the brace.
But the battle was far from over, and I was constantly falling down
I proudly carried the name my friends called me
"Hey, Stumble Butt" as I pulled myself up from the ground
Yet they would pump me on the handle bars, because I could not yet ride a bike
Or they would stop short of the summit, when my leg hurt too much to finish an easy hike
Saying "we're not worried, the mountain will be there tomorrow"
Those words still ring within my heart
The day came when the doctor said "there just might be some hope"
I think we can make it so the boy can run, if we cut a few tendons and reattach them over there
It may take two years or maybe three; he may pay a price when he gets "old"
But before he could finish, Dad just looked at Mom and said "let him run, let him run"

So after a reset of crutches, casts, and braces, I got to start anew
Running in the moonlight, sailing on the sea, hunting with a friend,
Doing jobs that challenged the healthiest of men
Living Life with my hair on fire, never knowing if it might end
It's not that I lead a special life or that I did something great or grand
It's that I appreciated every moment a friend waited, every step my parents gave to me
And every moment, I got to walk blissfully in the sun
The pain has never really left me, and I knew that a price would someday have to be paid
But now they have a new word that they whisper, Post-Polio is its name
So it's back to the old crutches and braces, and pain to end each day
But I still feel like a bird when my loved ones touch me
And I still wonder what new blessings are coming, because of this "old bum leg."
THINKING PROBLEMS AND AGING WITH A DISABILITY

Cognition refers to thinking activities such as remembering, paying attention, learning new things, planning and making decisions.

Some changes in cognition are normal as people get older. For persons who are aging with physical disability, cognitive changes may impact your ability to cope with challenges related to your disability.

Some people have minor changes in thinking that occur every once in a while and others have larger thinking problems that occur more often. Even minor changes in thinking as you age can cause challenges in your daily life and affect your overall quality of life.

What are some causes of cognitive problems?

- Some disabling conditions, such as multiple sclerosis, directly affect structures of the brain, which can lead to cognitive problems.
- Symptoms that are often part of a medical condition, such as fatigue, depression, & pain, can cause or contribute to thinking problems.
- Cognitive problems can also make medical symptoms worse, creating a negative cycle. This means that as your other symptoms get worse, your thinking problems also get worse.
- Some medications may cause thinking difficulties & older adults may be more vulnerable to cognitive problems related to certain medication. It is important to discuss any concerns you have with your health care provider.

What kind of thinking problems can happen with aging?

- Memory problems are the most common type of thinking problems in aging.
- It is more difficult to hold information in our mind for a brief period to perform a task, such as following instructions or figuring out how much to tip (referred to as working memory).
- Details like names and places are harder to recall.
- It is more difficult to remember something you are supposed to do in the future, such as taking your medication or going to a doctor's appointment.
- Attention or the ability to concentrate is also commonly affected. You may be more distractible, and multi-tasking is much more difficult.
- Thinking can become slower so completing simple tasks can require more concentration and time. Problems with communication may also happen. For example, you may have difficulty finding words or keeping up with a conversation.
- Making decisions can be more difficult.

How can thinking problems impact your daily life?

- Cognitive problems limit how much you may be able to participate in daily activities, such as work and social relationships.
- Thinking problems may impact your independence.
- If you have difficulties with attention and your thinking has slowed, driving may become dangerous.
- You may also have problems managing your finances due to challenges staying organized and making decisions.
- Thinking problems can lead to premature retirement and unemployment.
- Changes in thinking can also cause added anxiety and stress in your life. Fortunately, there are ways you can improve your thinking and reduce the negative impact thinking problems may have on your life.

What You Can Do - Tips for Addressing Your Thinking Problems

Changes in thinking can be managed by increasing awareness about your thinking problems, doing activities to improve your thinking and developing planning strategies. It is important to get started early to put supports in place to help with your thinking problems.
Understand Your Thinking Problems
Being aware of your thinking problems and how they may affect you is an important first step.

Problems with cognition are often gradual and may not be immediately noticeable to others, but they may be noticeable to you. Here are some ways to help you understand your thinking problems:

- Identify triggers that can worsen your thinking problems, such as lack of sleep, stress, or certain medication and write down these triggers.
- Talk with your health care provider about your thinking problems and triggers. Your health care provider may refer you to a neuropsychologist. A neuropsychologist can provide an assessment of your cognitive function to identify areas of strengths and weaknesses. This may be particularly important if you are working or there is concern about safety.

Simplify Your Day
- Set up a daily routine. This can make your day more predictable and less stressful.
- Pace yourself during the day.
- Break complex activities down into multiple easier parts.
- Do one thing at a time when possible. Multi-tasking can often make thinking more difficult.
- Prioritize what needs to be done. Do those things first, then less important things later.
- Schedule activities that will require more focus and concentration during times of day when your thinking is typically better.
- Avoid triggers in your environment that make thinking more difficult.
- Avoid visual or sound distractions.
- For example, keep your desk neat at work, and turn down the radio or close the windows if it's noisy outside.
- Avoid socializing in crowded and loud environments.

Learn New Methods That Help With Thinking
Try different methods that may help with your thinking problems and see what works best for you. Be open to trying new methods. Some methods you may find helpful include:

- Writing things down.
- Using memory aids such as post-it notes, daily planners, or calendars.
- Setting a timer on your watch or phone can be a helpful tool to remind you to take medication or go to an appointment.

Your health care provider may also refer you to a Speech Therapist or a Rehabilitation Psychologist, who are both skilled professionals that can help you learn new methods and problem-solve. They may also suggest activities and making lifestyle changes that can help reduce problems with thinking or even improve thinking skills.

Maintain an Active and Healthy Lifestyle
Get physically active. Research has shown that physical activity, such as walking, can help maintain good cognitive health and may prevent cognitive decline. Physical activity can also help improve sleep, fight fatigue, and improve mood, all of which contribute to your cognition.

- Engage in mentally stimulating activities you enjoy.
- Read a new book, do crosswords or Sudoku's.
- Challenge yourself by learning something new. Research suggests that this may be particularly effective, as it helps build new neural connections in the brain.
- Be socially active. Good conversation can stimulate new thinking.
- Play an instrument or listen to music.
- Get enough sleep.
- Take frequent rest breaks during the day. Some people find that resting in silence is most effective (turn off phone, TV, etc.). This will help minimize fatigue and refocus your thinking.
- Maintain a healthy diet. Eating right can help you avoid fatigue and increase your energy level.
Improve your mood, depression can significantly affect your ability to think. Try to minimize stress and anxiety.

Things to avoid: Smoking, abusing alcohol, using illicit drugs and misusing prescription or over-the-counter medications.

Resources
Centers for Disease Control and Prevention: www.cdc.gov/aging/healthybrain

National Council on Aging (NCOA) Center for Health Aging, Behavioral Health: www.ncoa.org/improve-health/center-for-health-/aging/behavioral-health/

National Institute on Aging: www.nia.nih.gov
National Institute of Health Senior Health: http://nihseniorhealth.gov/

References


Disclaimer
This information is not meant to replace the advice from a medical professional. You should consult your health care provider regarding specific medical concerns or treatment.

Authorship
Content is based on research evidence and/or professional consensus of faculty at the University of Washington Aging and Physical Disability Rehabilitation Research and Training Center (AGERRTC).

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HELP WANTED!!

WITH THE FOREGOING IN MIND, YOUR EDITOR (age 86) WANTS TO TRAIN HER REPLACEMENT FOR THE FUTURE. IT'S A FUN JOB, mostly just reviewing other newsletters for articles to reprint! This newsletter is in Microsoft Word format and you would need to make PDF'S of it and E-MAIL it to the proofers, printer and Easter Seals. Some original writing is needed to describe our Events. Originally, I did spreadsheets before my brain started to leave town! PLEASE CALL 303-937-5052 or E-Mail to janetandjere@SoftHome.net.
OUR EXECUTIVE COMMITTEE MEMBERS

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Colorado Post-Polio Support Groups Schedules

Support groups usually have a plan, an activity or program for each meeting. In bad weather, call the contact person to make sure the meeting will be held.

**Aurora** - Meets 4th Thursday of each month, 11:00am to Noon  
Contact: Sandy Abbott – 303-646-7346 - sandya65@outlook.com

**Colorado Springs** - Meets 2nd Saturday of each month, 10:00am to Noon  
Contact: Linda Groth - 719-633-1497 – (Call for location)

**Grand Junction** – This revived group is getting underway again. For information  
Contact: Loran Dake - 970-241-7825 - Iorandake@msn.com or Chuck Langan - 970-270-0654

**Lakewood** - Meets the 2nd Tuesday of every other month, 11:00am to 1:00pm at The Egg and I.  
Contact: - We're looking for a new coordinator for 2016

**Northern Colorado (Fort Collins)** - Meets 4th Saturday of each month, 10:00am to Noon - Contact: Peter Way - NOCOPolio@gmail.com – 870-460-6164

**Pueblo** – Looking for new time and meeting place. Call for details.  
Contact: Maureen Sullivan - 719- 561-3182 - mmsosal2005@yahoo.com – or  
Mary Agnes Leonard – 719-544-4789 – maryagnesleonard@gmail.com

**Survivors South** -- Meets 2nd Tuesday of each month at The Egg & I in Littleton at 11:30 am - Contact: Bobbye Gibson – 303-927-6890 - calliecat1@comcast.net

**Thornton** - Meets 1st Saturday of the month (Call for meeting dates), 10:00am to Noon - Contact: Paul Puma - 303-453-9552
The ages (35 to 85) of folks who attended the Retreat, confirmed the range of years we need to plan for continuing our efforts to serve Polio survivors. We are grateful to report that with the help of some serious, major donors, we are building reserves. Even though they don’t wish to brag, it’s because of our “Angel” donors we can build savings for the future.

It is still necessary to receive help from our many regular donors since it is they who support our overhead, leaving funds for our outreach and special programs.

Every dollar you contribute supports our outreach efforts, support groups, education and this newsletter. Please complete this form, detach it, and mail it to Nancy Hanson at Easter Seals Colorado, address below. Your contribution will be gratefully acknowledged.

**Remember**, many supporters donate in memory of a loved one or include gifts to Colorado Post-Polio in their wills or trusts

To ensure that we receive 100% of your donation, any contributions should be payable to Easter Seals Colorado and PLEASE WRITE "POST-POLIO" IN THE MEMO LINE. Your contribution will be gratefully acknowledged.

Thank you!

Name:________________________________________

Address:__________________________________________________________________________

City, State, Zip:___________________________________________________________________

Phone:____________________________________________________________________________

E-Mail________________________________________

Mail to: Easter Seals Colorado, 5755 West Alameda Ave, Lakewood, CO  80226
This Is YOUR Newsletter-----

"Connections" is the official news publication of the Colorado Post-Polio Program. The opinions are those of the individual contributors, and do not necessarily constitute an endorsement or approval by either the Colorado Post-Polio Council or Easter Seals Colorado. (Always check with your personal physician for all medical questions and concerns.)

We invite not only your comments about this newsletter, but your personal stories, other story ideas, and contributions. Tell us what topics you want to read about in future issues. If you have article ideas or suggestions, are willing to write a short article, tell your personal story or you'd like to review a book, please call Janet Thompson at 303-937-5052 or send an e-mail to her at janetandjere@SoftHome.net, or write to:

Colorado Post-Polio Connections  
c/o Easter Seals Colorado  
5755 W. Alameda Ave.  
Lakewood, CO 80226

If you prefer to receive this newsletter online or change your mailing label information, please notify Nancy Hanson at Easter Seals Colorado, at 303-233-1666, ext. 237 or email her at: Nhanson@eastersealscolorado.org